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Assessment of the status of A National Action Plan for Cancer Survivorship in the USA

Judith Lee Smith,

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA

Lori A. Pollack,

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA. Prevention and Response Branch, Division of Healthcare Quality Promotion, Centers for Disease Control and Prevention, Atlanta, GA, USA

Juan L. Rodriguez,

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA

Nikki A. Hawkins,

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA

Tenbroeck Smith,

Behavioral Research Center, Intramural Research Department, American Cancer Society, Atlanta, GA, USA

Ruth Rechis,

Livestrong Foundation, Austin, TX, USA

Andy Miller,

Livestrong Foundation, Austin, TX, USA

Anne Willis,

National Coalition for Cancer Survivorship, Silver Spring, MD, USA

Helen Miller,

CancerCare, New York, NY, USA

Ingrid J. Hall,

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA

Temeika L. Fairley, and

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mail Stop K-55, Atlanta, GA 30341, USA

Brenda Stone-Wiggins

RTI International, Research Triangle Park, NC, USA

Judith Lee Smith: JLeeSmith@cdc.gov

Abstract

Purpose—There are currently more than 12 million cancer survivors in the USA. Survivors face many issues related to cancer and treatment that are outside the purview of the clinical care system. Therefore, understanding and providing for the evolving needs of cancer survivors offers challenges and opportunities for the public health system. In 2004, the Centers for Disease Control and Prevention and the Lance Armstrong Foundation, now the Livestrong Foundation, partnered with national cancer survivorship organizations to develop the *National Action Plan for Cancer Survivorship* (NAPCS). This plan outlines public health strategies to address the needs of cancer survivors. To date, no assessment of NAPCS strategies and their alignment with domestic cancer survivorship activities has been conducted.

Methods—The activities of five national organizations with organized public health agendas about cancer survivorship were assessed qualitatively during 2003–2007. Using the NAPCS as an organizing framework, interviews were conducted with key informants from all participating organizations. Interview responses were supplemented with relevant materials from informants and reviews of the organizations' websites.

Results—Strategies associated with surveillance and applied research; communication, education, and training; and programs, policy, and infrastructure represent a large amount of the organizational efforts. However, there are gaps in research on preventive interventions, evaluation of implemented activities, and translation.

Conclusions—Numerous NAPCS strategies have been implemented. Future efforts of national cancer survivorship organizations should include rigorous evaluation of implemented activities, increased translation of research to practice, and assessment of dissemination efforts.

Implications for Cancer Survivors—The results of this descriptive assessment provide cancer survivors, cancer survivorship organizations, researchers, providers, and policy makers with initial information about cancer survivorship public health efforts in the USA. Additionally, results suggest areas in need of further attention and next steps in advancing the national cancer survivorship public health agenda.

Keywords

Cancer survivorship; National Action Plan for Cancer Survivorship; Public health; Assessment; Evaluation

Introduction and background

A cancer survivor is a person who has received a diagnosis of cancer, from the time of diagnosis throughout the remainder of their life [1, 2]. In 2007, there were 11.7 million cancer survivors in the USA [3]. There are now more than 12 million cancer survivors in the USA [4]. The population of cancer survivors is expected to continue to grow as the population ages, as early detection through screening improves, and as medical advances

continue [5, 6]. Understanding and providing for the evolving needs of a growing number of cancer survivors offers challenges and opportunities for the public health system. Survivors encounter many issues that fall outside the immediate scope and responsibility of their cancer treatment team—often years after treatment [7–10]. Survivors may face needs associated with rehabilitation [11–13], information [14, 15], psychological functioning [16, 17], finances [18], and aging [19, 20].

To address these challenges, the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation, now the Livestrong Foundation, collaborated to develop the *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* (NAPCS) [1]. The NAPCS resulted from the structured deliberation of a multidisciplinary expert panel of cancer survivors, clinicians, and researchers in the fields of public health and cancer survivorship. The objective of the resulting plan was to provide a guide to national, state, and local public health and cancer survivorship organizations as they work to address the needs of cancer survivors and allocate resources to cancer survivorship initiatives.

The expert panel identified four public health domains: (a) surveillance and applied research; (b) communication, education, and training; (c) programs, policies, and infrastructure; and (d) access to quality care and services, as well as one cross-cutting category. Strategies that were associated with more than one domain were classified as cross-cutting. Within the cross-cutting category and the four domains, the expert panel described 28 priority public health needs of cancer survivors and 96 strategies to address the identified needs [1].

After the creation of the NAPCS, an assessment was conducted with a subset of national cancer survivorship organizations that participated in the original expert panel. The assessment focused broadly on two questions: (a) which NAPCS strategies were appropriate to the missions of the selected organizations? (i.e., applicability) and (b) which NAPCS strategies were associated with ongoing activities at the organizations? (i.e., implementation). We report these findings and provide guidance about future national cancer survivorship efforts.

Methods

Selection of organizations

For this initial assessment of the NAPCS, CDC included organizations that were leading national cancer survivorship programmatic and advocacy activities [21] and had participated in the original expert panel. The following organizations were selected for assessment: the American Cancer Society; CancerCare; CDC, Division of Cancer Prevention and Control; Livestrong Foundation; and the National Coalition for Cancer Survivorship.

Project timeline

This report summarizes activities of the participating organizations during July 2003–August 2007. The data were collected in two phases. The first phase of data collection covered activities from July 2003 to July 2005. After completion of an initial report in 2007, organizations provided a supplemental report of activities completed during August 2005–

August 2007 (phase 2). Analysis and synthesis from interviews and supplemental reports were conducted during 2008–2009.

Instrumentation

An interview protocol was developed to guide respondents systematically through all the strategies in the NAPCS. Activities included in this assessment were limited to those initiated or led by the organization and directly relevant to the strategies outlined in the NAPCS. The interview protocol, developed by Research Triangle Institute International (RTI) with technical assistance from CDC, consisted of eight sections with questions covering respondent background, review of priority needs, alignment of activities with the strategies in the cross-cutting category and each of the four domains, and additional comments. The structure of the interview allowed flexibility for multiple respondents to participate in a particular section(s) or the full interview protocol.

Interview methodology

CDC contacted the organizations to inform them about the assessment. RTI interviewed the lead contact person at each organization to explain the interview process, identify the appropriate respondents, and schedule on-site or telephone interviews. RTI asked respondents to participate in an interview assessing the applicability and implementation of the NAPCS within their respective organizations. Experienced RTI interviewers, who were knowledgeable about cancer prevention and control, conducted the interviews with respondents from each organization. To supplement the data collected during the interviews, the interviewers also reviewed reports and other relevant materials provided by the respondents and organizations' websites.

Data collection and analysis

For this assessment, a Microsoft Access database was developed to systematically capture and track responses about the applicability and implementation of NAPCS strategies. Data were entered into the database, either after the face-to-face interview or during the telephone interview.

A two-step process was employed to assess the NAPCS strategies. The first step was to determine if the strategy was applicable to the missions of the organizations. Applicability or *fit* for any strategy was achieved if at least one of the five organizations reported that the strategy was consistent with its mission. The second step was to determine whether the organizations had implemented the strategy. Implementation or *action* for any strategy was achieved if at least one organization reported an activity, consistent with the NAPCS strategies that was initiated or led by the organization. Strategies were then coded into one of four mutually exclusive categories: fit, action taken (i.e., implementation); fit, no action taken (i.e., gaps in implementation); no fit (i.e., no organizational fit); and other (i.e., activity reported was not consistent with NAPCS strategies or was not initiated or led by organization). This report will discuss the findings for the first three categories.

RTI research staff, who had not been involved in the interviews, completed data extraction and entry. Next, RTI research staff reviewed the data to identify and correct any data entry

errors. Finally, respondents reviewed their responses to ensure completeness and accuracy. To facilitate this review, a PDF file of the organization's data report was sent to the lead contact person at each respective organization. This individual distributed the report to all respondents, collected their feedback, and prepared one edited data report with all revisions and returned the report to RTI.

Results

Respondents

Twenty-two respondents from the five organizations were interviewed: 9 face to face and 13 by telephone. The number of respondents from each organization ranged from 1 to 8. Respondents included those in leadership positions (e.g., directors, vice presidents), supervisors with responsibilities in NAPCS domains (e.g., surveillance, education, policy), and staff managing daily cancer survivorship activities within their respective organizations. The length of the interviews ranged from 60 to 90 min.

Overall, there was 95 % applicability—with 91 of the 96 NAPCS strategies consistent with the mission of at least one organization. Of the applicable strategies, 76 % (69 of 91 strategies) had activities led or initiated by one of the five organizations; 24 % (22 of 91 strategies) were not being implemented (Table 1). There are nine NAPCS priority needs that do not have any associated strategies in their assigned domains; however, these priority needs are detailed in the cross-cutting category [1]. Table 2 lists these nine priority needs and the corresponding cross-cutting priority need. Results for applicability and implementation are presented for all of the strategies in the cutting-cutting category and the four domains—below and on Table 3. Unanimous implementation was rare with most strategies undertaken by one to three organizations.

Cross-cutting needs and strategies

Applicability—Cross-cutting needs and strategies are the systems, tools, programs, and processes that are important to “advancing cancer survivorship within the realm of public health” [1] and are associated with more than one domain in the NAPCS. There are 32 cross-cutting strategies in the NAPCS. Most strategies (30 of 32, 94 %) were consistent with the mission of at least one organization. Only two cross-cutting strategies (2 of 32, 6 %) were rated as *no fit* by all five participating organizations. These strategies were associated with charging outside groups to develop clinical practice guidelines and requiring ongoing training for the health care workforce.

Implementation—Fifty-six percent (18 of 32) of cross-cutting strategies were implemented by the organizations. Organizations reported work in areas related to research and initial practice with patient navigation systems and development and dissemination of public education programs for cancer survivors. A variety of channels were used for informing and assisting survivors, families, and caregivers. Examples include an online forum for posttreatment cancer survivors, telephone education workshops, support groups (e.g., online, face to face, and professionally facilitated), and print materials (e.g., newsletters, fact sheets, etc.). Several methods for disseminating best practices were

reported including telephone resource numbers, websites, distribution of print materials at professional conferences, and funding grantees to develop and disseminate educational programs and materials to priority populations. Research was being conducted to determine the needs of cancer survivors and their caregivers, assess patterns of care using cancer registry data, and assess the health care providers of older adult survivors.

Gaps in implementation—Thirty-eight percent (12 of 32) of cross-cutting strategies had not been implemented. The majority of these strategies were associated with developing infrastructure for a comprehensive database on cancer survivorship and establishment or dissemination of best practice guidelines. No organizations reported developing consensus on a set of data indicators for cancer survivorship data, developing policies to require insurance coverage for patient navigation, or developing strategies to recruit and retain quality service providers, among others.

Surveillance and applied research

Applicability—Cancer surveillance and applied research relates to the “systematic collection, analysis, and use of cancer data” and the application of that knowledge and understanding to “develop appropriate interventions” [1]. This domain has 17 strategies, and all were consistent with the mission of at least one organization.

Implementation—Seventy-six percent (13 of 17) of the strategies in this domain were implemented. Organizations reported a large amount of work on identifying factors associated with the health concerns of cancer survivors and identifying programs and services that best serve the needs of cancer survivors. For example, a population-based study examined the health behaviors and quality of life of adult cancer survivors [22–25]. Another study investigated the use of complementary and alternative medicine among prostate cancer patients [26]. Additional studies explored the effectiveness of nontraditional cancer support groups, reasons for nonreceipt of appropriate treatment among low-income women [27], and quality of life and treatment decision making for men with localized prostate cancer [28–30]. Other survivorship issues that were being assessed included family involvement in providing informal care and caregivers’ unmet needs and quality of life. Notably, all of these studies were focused on the adult cancer survivor population.

Gaps in implementation—Twenty-four percent (4 of 17) of surveillance and applied research strategies were not being implemented by the organizations. Conducting research on cancer control and prevention interventions for survivors and translating applied research into practice were the largest gaps. None of the organizations reported developing an inventory of existing preventive interventions for cancer survivors, conducting cost-effectiveness studies to assess interventions, customizing communication to specific cancer survivor populations, or incorporating cancer survivorship into the Guide to Community Preventive Services.

Communication, education, and training

Applicability—Communication, education, and training focused on “efforts aimed at increasing awareness of cancer survivorship efforts” and included communication with the

public and education for survivors and providers [1]. This domain has 17 strategies, and all were consistent with the mission of at least one organization.

Implementation—Organizations reported the most extensive implementation in this domain with action taken on 16 of 17 strategies (94 %). Activities included efforts to promote cancer survivorship as a chronic condition and educate policy and decision makers about long-term care and follow-up, quality of life and legal concerns, and the importance of increasing access to clinical trials. Methods to achieve these goals included one-time events (e.g., development and national release of an advocacy tool kit) and periodic activities (e.g., responding to inquiries from congressional staff) to longstanding institutionalized efforts (e.g., formally training survivors as advocates, hosting lobby days on Capitol Hill).

Organizations also reported developing resources to assist survivors with accessing information and providing these resources through a variety of distribution points. Several activities were focused on increasing survivors' access to web-based information and low-literacy materials and brochures.

Health care providers were targeted for education through cancer survivorship research conferences, telephone education workshops, and educational forums sponsored by professional organizations. Other opportunities for professional education were annual cancer survivorship workshop series, online continuing education modules, and public and professional education Listservs.

Gaps in implementation—Only one strategy in this domain had not been implemented: partner with advocacy groups to visit community practices and observe or educate local providers.

Programs, policies, and infrastructure

Applicability—Disseminating effective interventions, implementing supportive policies, and providing adequate resources and facilities are necessary to deliver services related to the continuum of care for survivors [1]. This domain has 12 strategies, and all were consistent with the mission of at least one organization.

Implementation—The majority of the strategies (10 of 12, 83 %) had been implemented in this domain. Efforts on conducting evidence-based programs and promoting changes in policy to support understanding cancer as a chronic disease were evident. Activities included testing approaches to increase screening for colorectal, prostate, and lung cancers and developing clearinghouses for cancer prevention and control information and best practices. Educating policy makers and health professionals about programs and activities using a variety of methods, including white papers and briefing materials for legislative staffers, was often reported. Organizations were also identifying insurance issues important to cancer survivors, including collecting data about challenges to receipt of services (e.g., ineligibility for existing public programs) and advocacy regarding insurance issues (e.g., online resource and educational materials).

Gaps in implementation—The strategies (2 of 12, 17 %) in this domain that were not implemented by any organization were establishing criteria to determine which programs were using best practices and identifying and ranking programs according to best practices criteria.

Access to quality care and services

Applicability—Access to quality treatment, effective pain management, and appropriate end-of-life care are important to survivors at every stage of the cancer continuum [1, 31]. There are 18 strategies, and 83 % (15 of 18) were consistent with the mission in at least one organization. Three strategies did not fit the missions of the five organizations. These strategies included the development of targeted therapies to manage cancer, ensuring that survivors have access to palliative care and supportive teams, and review of chronic disease management plans to develop integrated management plans for cancer survivorship.

Implementation—Sixty-six percent (12 of 18) of the strategies were being met by activities of the organizations. Decision makers were informed about the needs of cancer survivors and the financial barriers that impede access for the uninsured and underinsured through presentations and exhibits at meetings for state cancer program directors and their partners. Advisory groups had been convened to discuss symptom management and palliative care. Additional activities included providing policy makers with survivors' stories about economic and insurance barriers and writing *amicus* (i.e., friends of the court) briefs regarding issues of concern to cancer survivors.

Gaps in implementation—Three of 18 strategies (17 %) were not implemented in this domain. Organizations had not provided training to providers about substance abuse to increase professional acceptance of prescribing pain medication, developed mechanisms to allow survivors to have ongoing follow-up with care team after primary treatment, or provided professional education on cancer survivorship.

Discussion

The results from this descriptive assessment provide valuable insight into the applicability and implementation of the NAPCS. The number of activities reported demonstrates that the participating organizations are leading numerous cancer survivorship public health efforts consistent with the NAPCS strategies. Importantly, this is the first assessment of US cancer survivorship activities and their alignment with strategies outlined in the NAPCS. This assessment provides cancer survivors, cancer survivorship organizations, researchers, providers, and policy makers with initial descriptive information about national cancer survivorship public health efforts and areas in need of further investment.

Many of the efforts are seen in the domains of communication, education, and training and programs, policies, and infrastructure. More than half of the NAPCS strategies associated with surveillance and applied research and cross-cutting needs are also being addressed by the organizations. Some gaps, however, have been identified. Several strategies were not considered mission-appropriate activities by the participating organizations, including: (1) charging groups to develop clinical practice guidelines, (2) requiring ongoing training to

ensure a quality workforce, (3) development of targeted therapies for cancer pain, (4) ensuring access to symptom management and palliative care supportive teams, and (5) modeling management care plans from other diseases to develop integrated multidisciplinary plans for cancer survivorship. This finding was understandable given that organizations focusing primarily on clinical service delivery were not included in this assessment. Some organizations, however, have developed targeted clinical guidelines. For example, in 2006, the American Society of Clinical Oncology published a clinical practice guideline for preservation of fertility in cancer survivors [32]. More recently, in 2012, the National Comprehensive Cancer Network published guidelines for childhood, adolescent, and young adult survivors [33].

Implications of this work must be considered concurrent with study limitations. Although the findings are a result of an extensive interview and qualitative data collection process, they are reflective of the knowledge and perspectives of the respondents. Every effort was made to identify key informants who were well informed about the cancer survivorship activities and initiatives in their respective organizations. Furthermore, all respondents were encouraged to seek additional relevant information from colleagues. Overreporting was mitigated because of the requirements for reporting of any activity—the activity had to be led or initiated by the organization and had to be specific to the strategies in the NAPCS. Organizations could not report an activity in which they did not have a lead role, thus, it was highly unlikely that multiple organizations could successfully report the same activity for any individual strategy. Additionally, the review of the data reports by RTI staff also ensured that the same activity was not counted twice for any strategy.

A final limitation must be noted about the timeline. As mentioned earlier, this is a report on activities from 2003 to 2007. The five participating organizations are engaged in national cancer survivorship public health efforts that are not included in this report. At the time of this assessment, however, activities related to research on preventive interventions, evaluation of implemented activities (e.g., impact of policy efforts, program effectiveness, cost effectiveness), and adapting and translating applied research into practice were limited. Rigorous evaluation and appropriate adaptation and translation of research are imperative to meaningfully assist and support survivors [34, 35].

Our findings suggest opportunities for national cancer survivorship organizations, future NAPCS expert panels, and future assessments of the NAPCS. Potential next steps for national cancer survivorship organizations may include review of the NAPCS strategies and ascertainment of continued relevance; tracking, rigorous evaluation, and reporting of the results of activities associated with the strategies; identification of methods to promote translation of research into practice; and assessment of dissemination efforts. In addition, organizations will have to continue to ensure that they are meeting the need of survivors comprehensively, including identification of emerging public health needs.

Future NAPCS expert panels may want to consider if strategies in the cross-cutting category should be formally incorporated into one or more domains, eliminated because of redundancy, or, conversely, are the most beneficial strategies to pursue because of potential impact or return on investment. An additional task may be to assess whether strategies

should be developed for the nine priority needs that currently do not have any associated strategies. These priority needs are discussed in greater detail in the cross-cutting category [1]; thus, a review may be warranted to consider whether or not these priority needs are more appropriate for that category. Finally, future assessments of the NAPCS may benefit from inclusion of organization(s) whose focus is clinical service delivery and probing further to understand why some strategies may lack implementation.

The scope and number of strategies that have been implemented demonstrates the benefit of having varied organizations focused on a public health issue and promoting coordinated and evidence-based programs. National cancer survivorship organizations should be encouraged to review and revise, if necessary, the NAPCS to ensure its continued relevance for cancer survivors. Finally, comprehensive evaluation of the progress in meeting the priority needs and strategies in the NAPCS will be essential as cancer survivorship organizations, researchers, providers, and policy makers endeavor to address the needs of cancer survivors.

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Table 1

Applicability and implementation of NAPCS category/domains

Category/domain	Number of NAPCS strategies	Fit ^d n (%)	No fit ^b n (%)	Fit, action taken	
				Yes ^c n (%)	No ^d n (%)
Cross-cutting	32	30 (94 %)	2 (6 %)	18 (56 %)	12 (38 %)
Surveillance and applied research	17	17 (100 %)	0	13 (76 %)	4 (24 %)
Communication, education, and training	17	17 (100 %)	0	16 (94 %)	1 (6 %)
Programs, policies, and infrastructure	12	12 (100 %)	0	10 (83 %)	2 (17 %)
Access to quality care and services	18	15 (83 %)	3 (17 %)	12 (66 %)	3 (17 %)
Total	96	91	5	69	22

^a Fit: at least one organization reported that strategy was consistent with mission^b No fit: no organization reported that strategy was consistent with mission^c Fit, action taken (yes): number of applicable strategies implemented^d Fit, action taken (no): number of applicable strategies not implemented

Table 2

NAPCS priority needs without specific strategies, by domain with corresponding cross-cutting priority need

Domain	Priority need(s)	Corresponding cross-cutting priority need
Surveillance and applied research	Enhance the existing surveillance and applied research infrastructure	Develop an infrastructure for a comprehensive database on cancer survivorship
Communication, education, and training	Empower survivors with advocacy skills	Develop and disseminate public education programs that empower cancer survivors to make informed decisions
	Develop, test, maintain, and promote patient navigation systems for people living with cancer	Develop, test, maintain and promote patient navigation systems that can facilitate optimum care for cancer survivors
Programs, policies, and infrastructure	Develop, test, maintain, and promote patient navigation or case management programs that facilitate optimum care	Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors
	Develop and disseminate public education programs that empower survivors to make informed decisions	Develop and disseminate public education programs that empower cancer survivors to make informed decisions
	Establish clinical practice guidelines for each stage of cancer survivorship	Establish and/or disseminate clinical practice guidelines for each stage of cancer survivorship
	Develop infrastructure to obtain quality data on all cancer management activities to support programmatic action	Develop an infrastructure for a comprehensive database on cancer survivorship
Access to quality care and services	Develop, test, maintain, and promote a patient navigation system for cancer survivors	Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors
	Establish and/or disseminate guidelines that support quality and timely service provision to cancer survivors	Establish and/or disseminate clinical practice guidelines for each stage of cancer survivorship

Table 3

Applicability and implementation of NAPCS strategies, by category/domain

Category/domain	Priority need	Strategy	No fit	Fit: action taken	
				Yes	No
Cross-cutting	Develop an infrastructure for a comprehensive data base on cancer survivorship				
		Develop a national work group or task force of diverse organizations, representing private, nonprofit, and governmental agencies, to identify data needs for ongoing follow-up and confidential monitoring of cancer survivorship issues (e.g., treatment course and outcomes, quality-of-life indicators, long-term effects of diagnosis and treatment)			X
		Assess existing data on cancer survivors to identify gaps in order to determine areas of future research	X		
		Develop a consensus on a set of data items or indicators used in the collection and analysis of cancer survivorship data, including data needed for long-term follow-up on survivors			X
		Improve coordination among existing databases [e.g., National Program of Cancer Registries (NPCR), Behavioral Risk Factor Surveillance System (BRFSS), Surveillance Epidemiology and End Results (SEER)], and add data variables or indicators, where possible, to collect supplementary information on cancer survivors			X
	Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors	Develop a centralized resource center (i.e., clearing-house) that includes linkages to all existing data sources and that provides for longitudinal data collection, monitoring, and follow-up			X
		Increase the number and types of funding opportunities to enable a broader range of researchers to participate in survivorship surveillance activities	X		
		Use existing information technology to gather data on cancer diagnosis, treatment, and long-term issues and report the data in a timely manner	X		
		Provide widespread access to public data sets as quickly as possible to enhance research activities	X		
		Establish infrastructure of the patient navigation system, consisting of appropriate existing national organizations, to implement a national program with consistent delivery of services for cancer survivors	X		
		Promote universal input and buy-in by having patient navigation system co-branded and co-owned by all appropriate organizations	X		
		Identify existing types of patient navigation systems delivered in a variety of locations or through different mechanisms (e.g., rural, urban, online, print, telephone, clinical trials) and determine those that are considered best practices	X		
		Develop a database of existing and tested patient navigator tools/programs and educate survivors and others at the national, state, and community levels on their use	X		
		Plan, develop, and incorporate patient navigation systems into state comprehensive cancer control plans			X

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
	Establish and/or disseminate clinical practice guidelines for each stage of cancer survivorship	Develop policies to require insurance coverage of patient navigation services			X
		Develop effective patient navigator tools that address issues of disparity (e.g., race, ethnicity, education, geography, income, gender) among survivors		X	
		Encourage cancer survivors to volunteer their time (in-kind) to serve as individual navigators servicing other survivors		X	
		Charge appropriate groups working on cancer survivorship issues [e.g., National Comprehensive Cancer Network, American Society of Clinical Oncology, National Coalition for Cancer Survivorship (NCCS)] to develop clinical practice guidelines specific to each stage of cancer survivorship	X		
	Develop and disseminate public education programs that empower cancer survivors to make informed decisions	Establish a centralized location for housing these guidelines [e.g., National Guidelines Clearinghouse, Cancer Information Service (CIS)]			X
		Develop both consumer and health care provider versions of each clinical practice guideline and disseminate through multiple channels and organizations		X	
		Require that programs funded by public health organizations include implementation of clinical practice guidelines [e.g., state cancer plans, Comprehensive Cancer Control (CCC) Programs]			X
		Ensure accessibility of services named in each clinical practice guideline			X
		Conduct ongoing evaluation of guidelines and use results to assess utilization. Modify guidelines as needed			X
		Provide training to cancer and noncancer health professionals about guidelines to maximize workforce development		X	
		Ensure quality workforce by requiring ongoing training on such topics as cultural sensitivity and palliative care	X		
		Assess gaps in the health care workforce and develop strategies to recruit and retain quality service providers			X
		Form a national Task Force to develop programs addressing public education among survivors, and create a multifaceted strategic plan around this issue		X	
		Identify existing resources available to survivors to facilitate informed decision making and advocacy skills, and develop programs or materials where information is lacking		X	
	Conduct ongoing evaluation of all activities to determine	Charge the national Task Force with implementing marketing strategies and a multimedia campaign to effectively educate survivors about issues and available education programs, using numerous modes for communication (e.g., Internet, print media)		X	
		Disseminate and encourage implementation of best practices for enhancing informed decision making through a variety of venues (e.g., health care providers, advocacy groups, government agencies, legislators)		X	

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
Surveillance and applied research	Identify factors associated with the ongoing health concerns of cancer survivors	impacts and outcomes and ensure continuous quality improvement of services			
		impacts and outcomes and ensure continuous quality improvement of services			
		impacts and outcomes and ensure continuous quality improvement of services			
Surveillance and applied research	Identify factors associated with the ongoing health concerns of cancer survivors	Identify evaluation measures for each type of program or strategy implemented from the National Action Plan.		X	
		Conduct theoretically-based and scientifically-grounded studies to assess implementation.			X
		Disseminate evidence-based program evaluation findings through public health organizations and other venues in order to maximize use of information.		X	
		Initiate research studies to identify characteristics associated with certain types of cancer and/or secondary health concerns		X	
		Identify modifiable behaviors (e.g., limited physical activity, poor eating habits) that can be targeted with interventions to reduce the likelihood of additional health problems		X	
		Once more is known about which characteristics render survivors susceptible to health problems (e.g., different age groups), develop primary prevention education program to inform survivors about their susceptibility and any behavioral changes they can make to reduce their risk		X	
		Determine programs and services that best address the needs of cancer survivors			
		Gain a better understanding of how cancer survivors interact with the health care system by conducting national surveys [e.g., National Health Interview Survey (NHIS), BRFSS] to delineate the services delivered, usage pattern, and any problems in these areas		X	
		Enhance collaborative efforts among academic researchers and state health departments to develop research projects to increase the body of knowledge about the care and services that can be provided to survivors to reduce susceptibility to additional health problems		X	
		Identify, evaluate, and disseminate findings of the most effective models of survivorship care		X	
Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship		Incorporate lessons learned from this body of knowledge into state comprehensive cancer control plans		X	
		Develop an inventory of existing preventive interventions			X
		Evaluate programs in different public health settings to determine the effectiveness of particular intervention and establish best practices for cancer survivors		X	
Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship		Identify gaps in existing interventions through evaluation research		X	

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
Communication, education, and training	Translate applied research into practice	Develop interventions that address people at highest risk for developing other cancers/secondary health conditions		X	
		Conduct cost-effectiveness research of selected interventions			X
		Customize communication to specific cancer survivor populations, with specific focus on underserved communities, to increase awareness of available interventions and resources			X
		Incorporate cancer survivorship as an issue to address in the Guide to Community Preventive Services. This guide provides recommendations to preventive interventions that can be used in a community setting			X
		Develop tools/methods for translating research findings so that the general public can understand and apply the knowledge to their everyday life		X	
	Develop strategies to educate the public that cancer is a chronic disease that people can and do survive	Use research findings to educate cancer survivors and others (including providers, organizations, and advocates) on survivorship issues		X	
		Disseminate research findings to health care professionals and survivors through public health and other organizations, using a variety of venues (e.g., Internet, mail)		X	
		Convene a Task Force to identify existing educational information, and encourage partnerships to avoid duplication of efforts in developing new educational materials		X	
		Enhance a centralized information resource center, such as a clearinghouse (e.g., print, online), to provide access to consistent, scientifically valid, culturally appropriate health communication information		X	
		Promote the centralized information resource through a variety of media, including public service announcements for television, print, and the Internet		X	
Educate policy- and decision-makers about the role and value of long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors		Promote the concept of survivorship as a chronic condition that people can live with and not necessarily die from		X	
		Identify potential policy and decision makers and establish mechanisms to educate them on survivorship issues		X	
		Catalogue and characterize existing policies in order to identify gaps in survivor needs to address		X	

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
Teach survivors how to access and evaluate available information	Identify partnerships with those with an interest in national and/or state policies	Develop and implement specific strategies to educate each identified policy and decision maker group (e.g., legislators; local, state, and national regulators; health service administrators; advocacy groups; community-based organizations; health-related industries; insurance industry; pharmaceutical industry)		X	
		Develop a standardized system to assess the adequacy of available survivorship information		X	
		Develop resources to assist survivors in assessing survivorship information in a variety of formats (e.g., CD-ROM, pamphlets, Web pages, video)		X	
		Disseminate the above mentioned resources through a variety of distribution points (e.g., medical offices, cultural or faith-based community organizations, support groups, national and local associations) and through a centralized database that can be linked to other sources of reliable information		X	
		Provide technical assistance to groups whose materials do not meet the established evaluation criteria (i.e., do not maintain scientific validity) and enhance the quality of materials/products		X	
	Educate health care providers about cancer survivorship issues from diagnosis through long-term treatment effects and end-of-life care	Establish educational forums on survivorship in partnership with professional organizations		X	
		Educate health professional and para-professionals in local medical communities through grand rounds, tumor board meetings, and other venues		X	
		Partner with advocacy groups to visit community practices and observe/educate local providers about implications of and opportunities for improving quality of life			X
		Incorporate survivorship curricula into professional/para-professional training programs		X	
		Develop continuing education training in survivorship to deliver to a variety of health care professionals (e.g., internists, nurses)		X	
Programs, policies, and infrastructure	Identify and implement programs proven to be effective (i.e., best practices).	Establish quantifiable criteria to determine which programs are among the best practices for addressing cancer survivor needs			X
		Identify best practices based on agreed-upon criteria and rank order programs accordingly			X
		Identify gaps in survivorship research and provide funding to test new models and approaches		X	

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
Implement evidence-based cancer plans that include all stages of cancer survivorship		Establish a “clearinghouse” of information [e.g., Cancer Control P.L.A.N.E.T., Cancer Information Service (CIS)] using existing mechanisms for those programs identified as best practices		X	
		Promote this “clearinghouse” and otherwise disseminate information to programs, survivors, health care providers, and others. Use this clearinghouse to connect survivors to resources specific to their needs		X	
		Identify key leaders and experts in cancer survivorship in every state (especially survivors) to create a network of individuals to ensure that survivorship issues are being addressed through each cancer plan		X	
		Educate those involved in planning and developing state cancer plans on the importance of and issues related to cancer survivorship		X	
		Evaluate survivorship programs and publish and disseminate results		X	
Promote policy changes that support addressing cancer as a long-term chronic disease.		Link Comprehensive Cancer Control (CCC) Program and other funding so that cancer plans are required to comprehensively address survivorship		X	
		Develop and disseminate public education materials to educate policy makers, health professionals, and survivors on the stages of cancer survivorship.		X	
		Encourage insurance carriers and health plan administrators to provide for post-treatment and long-term follow-up services for cancer survivors.		X	
Access to quality care and services	Educate decision-makers about economic and insurance barriers related to health care for cancer survivors	Address terminology used in various settings, such as in formal policy and the media, at health care organizations, and among providers and insurance agencies, to modify policies to better reflect the stages of cancer survivorship		X	
		Convene a meeting of health care providers, cancer survivorship experts, researchers, and programmatic staff with the goal of developing strategies to educate policy makers about the unmet needs for cancer treatment of uninsured and underinsured survivors		X	
		Identify successful policy and legislative language as examples for state programs (and others), and identify key stakeholders (e.g., legislators, governors) needed to improve access to high quality treatment and other post-treatment follow-up services		X	
		Survey and analyze the insured population to determine the impact the individual's level of coverage has on timely access to care and receipt of follow-up care		X	
		Develop educational opportunities for decision makers of insurance carriers and health plans regarding policies that promote access to quality cancer care		X	

Category/domain	Priority need	Strategy	No fit	Fit, action taken	
				Yes	No
Assess and enhance provision of palliative services to cancer survivors		Collect baseline quantitative and qualitative data to assess the current status and location of palliative service provision, and characterize the experiences of survivors, their caregivers, and providers in relation to palliative care		X	
		Provide professional and public education to teach people about palliative care, how health care providers should administer such services, and how survivors and their caregivers can advocate for this care		X	
		Establish regulatory policies for licensing and agency responsibility for palliative care oversight		X	
		Provide training for medical personnel on the topic of substance abuse to help alleviate fears of misuse of pain medications and increase professional acceptance of prescribing pain control medications to cancer survivors			X
Establish integrated multidisciplinary teams of health care providers		Develop targeted therapies to manage cancer pain so that concerns about unintended consequences of pain medication administration can be avoided	X		
		Create centers of excellence (using pediatric cancer centers as a model) that provide comprehensive care to cancer survivors especially for rarer forms of cancer		X	
		Formulate policies that will improve access to services provided to survivors from an appropriate provider of choice		X	
		Promote and provide increased access to clinical trials and longitudinal follow-up through centers of excellence		X	
		Develop survivor-oriented Web sites to guide follow-up after completion of primary treatment		X	
		Develop mechanisms (e.g., password protected Web forum, telephone, mail) for survivors to have ongoing routine follow-up with their multidisciplinary team after primary treatment. Follow-up should be annual at a minimum			X
		Develop survivorship programs through appropriate partner organizations [e.g., the American College of Surgeons, Commission on Cancer, National Coalition for Cancer Survivorship (NCCS)] to provide professional education on cancer survivorship			X
		Ensure survivor access to symptom management/palliative care/supportive teams	X		
		Review management plans from other chronic disease models (e.g., diabetes) and use these as a basis to develop integrated multidisciplinary management plans for cancer survivorship	X		
		Ensure that integrated multidisciplinary management is available to survivors across the continuum of care		X	